

**Physical Activity
Recall Assessment
for People with
Spinal Cord Injury
(PARA-SCI)**



**ADMINISTRATION AND
SCORING MANUAL**



PHYSICAL ACTIVITY RECALL ASSESSMENT FOR PEOPLE WITH SPINAL CORD INJURY (PARA-SCI)

ADMINISTRATION AND SCORING MANUAL



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- PARA-SCI TRAINING TOOL (POWERPOINT DOCUMENT)
- QUALITY ASSURANCE CHECKLIST

PART 1:

WHAT IS THE PARA-SCI?

WHAT IS THE PARA-SCI?

The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI) is a self-report physical activity measure for people with spinal cord injury (SCI). The assessment is completed using a semi-structured interview protocol. It aims to measure the **type, frequency, duration,** and **intensity** of physical activity performed by persons with SCI who use a wheelchair as their primary mode of mobility. The PARA-SCI utilizes a 3-day recall format that is loosely based on the Seven-day Physical Activity Recall (PAR-7 (1)). The PARA-SCI measures activity actually performed over a three day time period (rather than activity that is usually performed). The PARA-SCI can be used among people with paraplegia or tetraplegia, and is designed to capture three categories of physical activity:

- **Leisure time physical activity (LTPA):** Activities that one chooses to do during free time, such as playing sports or working out at the gym.
- **Activities of Daily Living (ADL):** Activities that are part of one's daily routine, such as personal hygiene, household chores, work-related activity, passive leisure activity.
- **Cumulative activity:** The combination of LTPA and lifestyle activity.

KEY STRENGTHS OF THE PARA-SCI:

- Assesses intensity, including intensity for leisure activities and activities of daily living, in terms relevant to individuals with SCI
- Sensitive to low intensity activities (such as activities of daily living), which tend to comprise most of the SCI population's energy expenditure
- Content of PARA-SCI aims to capture activities that are part of this population's lifestyle (transfers, wheeling, etc.)
- A valid and reliable measure

THE PARA-SCI INTERVIEW PROTOCOL

The PARA-SCI utilizes a 3 day recall format loosely based on the Seven-day Physical Activity Recall (PAR-7; (1)). The scale was designed to measure activity actually performed over a specific period (i.e., last 3 days) rather than activity usually performed because people often have difficulty identifying what they "usually" do (9). A 3 day format was chosen over a 7 day recall format because a) people are very inaccurate at recalling activity for 7 days, unless the activity is unusual or very intense (10) and b) the accuracy of recall data diminishes sharply beyond the previous day (11). A 3 day recall format is considered valid and reliable in the general population (12).

During the PARA-SCI interview, participants are asked to recall activities they have done over the past 3 days, starting with yesterday. The interview is structured by dividing each recalled day into eight periods: Morning Routine, Breakfast, Morning, Lunch, Afternoon, Dinner, Evening, and Evening Routine. The Morning and Evening Routines are further subdivided into transferring, bowel and bladder management, bathing, personal hygiene, and dressing. See Supplementary Documents to view the actual PARA-SCI tool.

Guided by a series of flowcharts (see the PARA-SCI Training Tool), the interviewer asks about general activities performed during each period (e.g., "*In the morning, did you go out?*"). Affirmative responses are followed up with questions and prompts to help participants accurately recall the different specific types of physical

activity they may have performed as part of the general activity (e.g., *the general act of grocery shopping involves specific acts of wheeling, transferring into and out of a car, wheeling while lifting, and carrying objects*). The number of minutes spent on each specific activity is recorded and the activity is coded as either LTPA or ADL. Questions are also asked to help the respondent think about the intensity of each specific activity (e.g., “*did you wheel up or down an incline?*” and “*did you transfer upwards to a higher or downwards to a lower surface?*”). Participants rate the level of intensity of each specific activity as **mild, moderate, heavy,** or **nothing at all**, using the classification strategy described in the next section. See page 9 for a copy of the intensity classification chart.

WHY WAS THE PARA-SCI DEVELOPED?

A growing body of research suggests that physical activity can play an important role in reducing the risk of secondary impairments and chronic disease in the SCI population (2). For example, exercise training has been shown to reduce pain and depression among people with SCI (3, 4). With regard to the risk of chronic disease, there is preliminary evidence that among persons with SCI, physical activity is associated with positive changes in disease risk factors such as triglyceride levels (5), body fat (6), and insulin resistance (7). However, the specific activity types, durations, and intensities that produce these health outcomes have not yet been established within the SCI population. For example, it is not known how much wheeling (i.e., pushing one’s own wheelchair) should be done each week to reduce the risk of chronic disease, pain, and depression, or which lifestyle activities (e.g., gardening, household chores) might have health and fitness-enhancing benefits. The lack of such information makes it virtually impossible to develop physical activity guidelines for the SCI population, and study in this area has been impeded by the lack of a valid and reliable self-report measure of physical activity for people with SCI.

The most widely used type of physical activity measure is the self-report survey. Of the available self-report physical activity measures, the vast majority were developed for use in the general population and typically focus on measuring participation in recreational and sport activities that require independent ambulation (e.g., walking, jogging, playing sports). However, independent ambulation is uncommon among people with SCI and most of their energy expenditure is accounted for by activities of daily living and passive leisure activities. As a result, the existing self-report measures are insufficiently sensitive to measure very low intensity activities (8) that might account for the bulk of daily energy expenditure among people with SCI. The content of these measures also fails to capture activities that are part of this population’s lifestyle.

An SCI-specific physical activity measure would help researchers to fill a number of voids in the SCI and physical activity literature. In particular, a measure that assesses the performance of specific activities and their associated intensities would facilitate collection of epidemiological data necessary to develop health-promoting, physical activity prescription guidelines for people with SCI. An SCI-specific measure would also allow researchers to develop and test activity-enhancing interventions for the SCI population.

HOW WAS THE PARA-SCI DEVELOPED?

Construction of the PARA-SCI involved developing (a) a semistructured interview protocol for collecting physical activity information, and (b) a physical activity intensity classification system.

Development of the interview protocol:

The interview flowcharts were developed after initial consultation with two groups who described all of the activities that comprised the daily routines of people with SCI. The first group consisted of eight people with SCI and the second group consisted of seven SCI rehabilitation specialists (e.g., attendants, physiotherapists) and one parent of an individual with SCI. The interview flowcharts and questions were refined after consultation with a third group of 12 persons with SCI, who reviewed a preliminary draft of the flowcharts and provided additional information on activities performed by people with SCI and factors that could affect their intensity. Finally, four people with SCI (two paraplegic, two tetraplegic), who participated in the earlier development phases, evaluated the interview structure, flowcharts, questions, and prompts and deemed their content to be valid for assessing physical activity among people with SCI (i.e., they confirmed the PARA-SCI's face validity).

Refer to Martin Ginis et al. (13) for a detailed description of the interview protocol development.

Development of the intensity classification system:

Existing intensity classification systems for the general population (e.g., PAR-7) and people with other types of physical disabilities (e.g., Physical Activity and Disability Survey [PADS] (14)) are largely unsuitable for the SCI population. For instance, the PAR-7 instructs respondents to classify an activity's intensity relative to walking and running - obviously, inappropriate standards of comparison for people with SCI. The PADS instructs respondents to use their perspiration and respiration levels to determine activity intensity. This approach is also unsuitable because people with a lesion level above T6 do not have sympathetic innervation of the heart and do not experience the same physiological responses to activity as able-bodied individuals (15). Given these limitations, we needed to develop meaningful, appropriate definitional guidelines that would allow people with paraplegia and tetraplegia to accurately self-classify their activity as mild, moderate, or heavy.

We took an empirical approach to developing the intensity definitions. Participants with SCI underwent a progressive exercise test to determine the workload associated with their VO_{2peak} and the maximum load they could lift in one repetition (1RM) for chest press and biceps curl. Attainment of VO_{2peak} was corroborated by participants' self-report of maximal rating on the Borg Rating of Perceived Exertion (RPE) scale and an observed ratio of carbon dioxide produced to oxygen consumed in excess of 1.00. Approximately one week later, participants repeated exercises at individually prescribed mild, moderate, and heavy intensity based on percentages of their VO_{2peak} and 1RM as defined by the American College of Sports Medicine guidelines (16), and again completed Borg's RPE scale. After each exercise was performed, participants completed a structured interview regarding their in-task physiological and psychological states. Based on the responses most frequently and uniquely associated with each intensity level, a set of definitions were created for mild, moderate, and heavy intensity exercise. Please refer to Martin Ginis et al. (13) for a detailed and complete description of the development of the intensity classification system.

RELIABILITY AND VALIDITY OF THE PARA-SCI

The PARA-SCI measure of LTPA has demonstrated adequate test-retest reliability, criterion validity, construct validity, and responsiveness to change after a PA counselling intervention.

Please refer to the following articles for details regarding how reliability and validity of the PARA-SCI were examined, and the specific results of these analyses:

Martin Ginis, K. A., Latimer, A. E., Hicks, A. L., & Craven, B. C. (2005). Development and evaluation of an activity measure for people with spinal cord injury. *Medicine and Science in Sports and Exercise*, 37, 1099-1111.

Latimer, A. E., Martin Ginis, K.A., Craven, B. C., & Hicks, A. L. (2006). The physical activity recall assessment for people with spinal cord injury: validity. *Medicine and Science in Sports and Exercise*, 38, 208-216.

Latimer, A. E., Martin Ginis, K. A., & Arbour, K. P. (2006). The efficacy of an implementation intention intervention for promoting physical activity among individuals with spinal cord injury: a randomized controlled trial. *Rehabilitation Psychology*, 51, 273-280.

Tanhoffer, R. A., Tanhoffer, A. I. P., Raymond, J., Hills, A. P., & Davis, G. M. (2012). Comparison of methods to assess energy expenditure and physical activity in people with spinal cord injury. *The Journal of Spinal Cord Medicine*, 35, 35-45. Doi: <http://dx.doi.org/10.1179/2045772311Y.0000000046>.

STUDIES THAT HAVE USED OR CITED THE PARA-SCI - SEE APPENDIX

PART 2:

**HOW TO ADMINISTER
THE PARA-SCI**

PHYSICAL ACTIVITY INTENSITY CLASSIFICATION SYSTEM

The Physical Activity Intensity Classification System allows persons with paraplegia and tetraplegia to accurately self-classify their activity as mild, moderate, heavy, or nothing at all. For a detailed description of how this intensity classification system was developed, please refer to Martin Ginis et al. (13).

When administering the PARA-SCI over the telephone, the intensity classification chart (located on page 9 of this manual) should be sent to participants prior to the interview for review. Participants should also have the chart with them during the interview for referral. Descriptors for how participants may feel while working at each intensity are listed under each intensity category. These descriptors include **breathing, heart rate, muscles, skin,** and **mind** (i.e., level of concentration required to complete the activity).

Before conducting the interview the researcher should review this classification system with the participant. Page 12 of this manual contains a script for reviewing the intensity classification chart with the participant.

INTENSITY CLASSIFICATION CHART:

HOW HARD ARE YOU WORKING?

NOTHING AT ALL

Includes activities that even when you are doing them, you do not feel like you are working at all.

MILD

Includes physical activities that require you to do very light work. You should feel like you are working a little bit but overall you shouldn't find yourself working too hard

MODERATE

Includes physical activities that require some physical effort. You should feel like you are working somewhat hard but you should feel like you can keep going for a long time.

HEAVY

Includes physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short time before getting tired. These activities can be exhausting

HOW DOES YOUR BODY FEEL?

Breathing & Heart rate

Stays normal or is only a little bit harder and/or faster than normal

Noticeably harder and faster than normal but NOT extremely hard or fast

Fairly hard and much faster than normal.

Muscles

Everything is normal

Feel loose, warmed-up and relaxed. Feel normal temperature or a little bit warmer and not tired at all

Feel pumped and worked. Feel warmer than normal and starting to get tired after awhile.

Burn and feel tight and tense. Feel a lot warmer than normal and feel tired.

Skin

Normal temperature or is only a little bit warmer and not sweaty

A little bit warmer than normal and might be a little sweaty

Much warmer than normal and might be sweaty

Mind

You might feel very alert. Has no effect on concentration

Require some concentration to complete

Requires a lot of concentration (almost full) to complete

HOW TO CLASSIFY ACTIVITY TYPE: ACTIVITIES OF DAILY LIVING VS. LEISURE TIME PHYSICAL ACTIVITY

The PARA-SCI allows for classification of activities as either Leisure Time Physical Activity or Activities of Daily Living:

LEISURE TIME PHYSICAL ACTIVITY (LTPA)

LTPA includes all structured and unstructured physical activity that the individual chooses to do during free time.

Examples:

- Exercise
- Sport
- Taking the dog for a walk
- Playing catch

ACTIVITIES OF DAILY LIVING (ADL)

All other physical activity that is NOT coded as LTPA.

Examples:

- Physiotherapy*
- Stretching
- Shopping
- Cleaning

*"Physiotherapy" can have different meanings and encompass different activities across contexts and cultures. In the original PARA-SCI development and validation studies undertaken in Canada, physiotherapy was categorized as ADL. This decision was made after careful consideration of the activities that participants typically reported performing during physiotherapy; very often, these activities would not be considered fitness enhancing (e.g., passive stretching, range of motion activities) or leisure time activities (e.g., practicing transfers). In other contexts, however, users of the PARA-SCI may wish to categorize 'physiotherapy' as LTPA, depending on the types of activities undertaken during physiotherapy sessions.

THE "ACTIVITIES OF DAILY LIVING BY DEFAULT" RULE

There is a column labelled "Type" on the PARA-SCI tool where activity type can be recorded (see sample PARA-SCI reporting sheet on page 25). Always identify LTPA by marking "LTPA" in the type column. If this column is left blank, it can be assumed that the activity is an Activity of Daily Living.

If you are unsure of whether the activity should be coded as LTPA or ADL, ask the participant: "**Was this an activity that you chose to do during your free time?**" For example, if a participant states that he/she wheeled around the block and stopped by at a neighbour's house, ask the participant if wheeling was done during his/her free time for exercise, or if it was just a means of getting to the friend's house.

HOW TO ADMINISTER THE PARA-SCI: SURVEY SCRIPT

Page 9 contains the general telephone script used to administer the PARA-SCI. This script can be used for either phone or in-person interviews. The script is only a general outline asking participants to recall activities performed during each period of the day: Morning Routine, Breakfast, Morning, Lunch, Afternoon, Dinner, Evening, and Evening Routine. The morning and evening routines are further subdivided into transferring, bowel and bladder management, bathing, personal hygiene, and dressing.

Guided by a series of flowcharts, the interviewer asks about general activities performed during each period of the day (e.g., “In the morning, did you go out?”) Affirmative responses are followed up with questions and prompts to help participants accurately recall the different specific types of physical activity they may have performed as part of the general activity (e.g., the general act of grocery shopping involves specific acts of wheeling, transferring into and out of a car, wheeling while lifting, and carrying objects).

Questions are also asked to help the respondent think about the intensity of each specific activity (e.g., “did you wheel up or down an incline?” and “did you transfer upwards to a higher or downwards to a lower surface?”). Participants rate the level of intensity of each specific activity as mild, moderate, heavy, or nothing at all, using the classification strategy described on page 9 of the manual. The interviewer then asks the participant about the number of minutes spent on each specific activity and the activity is coded as either LTPA or ADL. The interviewer should always ask about the intensity of an activity first before asking about the duration of the activity. This way, if an activity is identified as “nothing at all,” time is not spent determining how long the participant engaged in the activity.

Generally, the interview takes about 20 to 25 minutes to complete. Time to complete the interview will vary depending on factors such as how active the participant is, difficulty in recalling activities, or how much prompting the participant requires.

***Note that the series of decision tree flowcharts used to guide interview questions have been organized as an interactive Powerpoint file (PARA-SCI Training Tool). Please refer to this Training Tool where sections of the script indicate to follow the decision tree. This tool is typically used to train interviewers to become accustomed to the logical flow of activities frequently reported in the SCI population. The tool is not typically used during the interview per se.

GENERAL PARA-SCI SCRIPT

Below is the general telephone script used to administer the PARA-SCI. This script can be used for either phone or in-person interviews.

"I would like you to tell me about the physical activities you have engaged in during the last three days. We will be starting with yesterday and going back three days. Please remember, this is a recall of *actual activities* for the three days, not a history of what you *usually* do. Also, keep in mind that physical activity includes any activity that required physical effort. That means I am interested in all of the activities you did in a day including the activities you did getting ready in the morning, at work, around the home, and during your leisure time. For example, your day might include activities such as transferring, getting dressed and wheeling to the shopping mall.

"I will also ask you to categorize the intensity of each physical activity you did into one of four groups; mild, moderate, heavy or nothing at all. Each of these intensities is described on the colorful sheet you received the other day (*review each definition with participant*). Notice that this sheet also provides a description of how you might feel at each intensity of activity. According to these definitions, what would be an example of a moderate physical activity for you personally?"

"The nothing at all category (light green), should include activities that even when you are doing them you do not feel like you are working at all. The mild activity category (dark blue) should include activities that require very light physical effort. You should feel like you are working a little bit but overall you shouldn't find yourself working too hard. The moderate activity category (yellow) should include activities that require some physical effort. You should feel like you are working somewhat hard but you should feel like you can keep going for a long time. The heavy activity category (red) should include physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short time before getting tired. These activities can be exhausting."

Setting the Stage:

"Today is _____ (i.e., Monday), so yesterday was _____ (i.e., Sunday). Think about what you did (Sunday) morning."

Morning

"What time did you wake up at?"

"Tell me about your morning routine. After you opened your eyes, what was the first thing you did?"

"What other activities did you do that required you to be physically active?"

"What did you do after your morning routine? Think about what you usually do. Did you do anything unusual?"
Follow decision tree.

Afternoon

"Tell me about your afternoon. What did you do for lunch?" *Follow decision tree.*

"What did you do after lunch? Think about what you usually do. Did you do anything unusual?"
Follow decision tree.

Evening

"What did you do for dinner?" *Follow decision tree.*

"What did you do after dinner? Think about what you usually do."

"Did you do anything unusual?" *Follow decision tree.*

"Tell me about your evening routine. What activities did you do that required you to be physically active?"

Intensity and Duration:

“Using the chart you have been given, how would you rate the intensity of that activity? How long did you work at that intensity?”

At the end of each day ask:

“Are there any physical activities that you might have forgotten? Did you have to take any trips to the bathroom during your day? Did you do any physical activity at work? Any other recreational or sport activities? Housework or gardening?”

Morning routine and evening routine day 2 and day 3:

“Compared with the morning/evening routine you just described (day 1), were there any differences in your morning/evening routine (day 2 and day 3)? “

If no differences, do not go through the morning or evening routine again. Indicate on recording sheet same as day 1.

On the last day of recall ask:

“Take a moment to think back over the course of the past 3 days; can you think of any activities that you may have forgotten?”

TIPS FOR FACILITATING RECALL

- **Review participant demographics.** So that you can tailor your questions to the participant, review the participant's demographic characteristics before you begin the interview.
- **Activity.** Outings: Did you leave your home? Weather: What was the weather like outside? Health/illness: How were you feeling? Holidays: It was [insert holiday] yesterday. Did you do anything special?
- **Intensity.** Did that activity make you feel similar to how you feel when you are [give example of moderate intensity activity identified earlier], or is easier or harder? Using the chart you have been given, how would you rate the intensity of that activity?
- **Duration.** How long did you work at that intensity? How much of that time was spent sitting still or taking breaks?
- **At the end of each day ask:**

Are there any physical activities that you might have forgotten? Did you have to take any trips to the bathroom during your day (only ask this question if the participant indicated that toileting is a physical activity during the morning routine or if he/she has to transfer onto the toilet each time). Did you do any physical activity at work? Any other recreational or sport activities? Housework or gardening? Were there any other activities you might have done?

- **Activities Often Forgotten:**
 - Transfers
 - Consider chunking transfers together e.g., how hard are you working to get into your car? How many times did you get in when you were running errands? Record number of transfers x time.
 - Bathroom trips
 - Childcare
 - Grocery shopping
 - Cleaning
 - Sweeping/vacuuming
 - Laundry
 - Watering plants
 - Making the bed
 - Taking garbage and recycling out

TIPS FROM PREVIOUS AND CURRENT PARA-SCI INTERVIEWERS

- Before starting the interview, inform the participant that going through the first day is going to seem long and very detailed, but once the interviewer gets a general idea of what is and is not physically intense for the participant, the other 2 days will be easier to get through. This tends to help keep the participant stay focused and remain patient throughout the process. After completing the first day, the interviewer may mention this point again, especially if the interviewer senses that the participant is growing impatient or is overwhelmed with the process. After completing Day 1, the interviewer might say something like, “Now that we have a good idea of what is and is not physically intense for you, these next 2 days should be much easier to complete”.
- When going through the introductory portion of the script and reviewing the intensity definitions, it may help to mention to the participant that we also want to know about/include activities that may only take a second or two of physical exertion. For example, for some participants, transferring may only take a few seconds but may still require physical exertion.
- It also helps to tell participants that we do not need to record activities that fit in the “Nothing At All” category. This additional information helps participants understand exactly what we are looking for and also helps eliminate reporting of unnecessary data.
- Referring to the participant’s demographic information to view their type/level of injury, Asia Impairment Scale (AIS) level, mode of mobility, etc., helps with anticipating the types of responses the particular participant may give. This information can act as a cue for additional questions that may be applicable to the participant. This information also allows the interviewer to be more sensitive to those with very high level injuries who may be very limited in terms of what they can physically do for themselves.
- Often when participants describe the second and third days, they tend to make statements such as, “My morning routine is always the same” or “Monday was exactly the same as yesterday.” Following these types of comments, the interviewer could remind the participant about the activities they recalled for previous days (without being too repetitive), and ask the participant if he/she did anything unusual or different. Often times participants will remember that they did in fact do something different outside of their usual routine, such as take a little longer to get dressed, or wheel to work instead of drive, etc.
- If participants state that they can’t remember what they did on a particular day, identifying something unusual or important that happened on that day might trigger recall. For example, mentioning an unusual weather event or news story that occurred on that particular day may serve as a helpful reminder for participants.
- If the PARA-SCI is used as part of a series of interviews, some interviewers find it helpful to administer the PARA-SCI near the end of the interview. By that point, more information about the participant (e.g., lifestyle, health, social relations, etc.) may be available, and participants may have mentioned events occurring in the last three days (e.g., “I had to go to the hospital the other night because I wasn’t feeling well”). These pieces of information are useful for helping participants recall activities and serve as cues for appropriate follow-up questions.
- Sometimes participants confuse pain with physical effort/exertion. When reviewing the definitions of intensity with the participant, it is a good idea to clarify that pain is different from physical effort. In other words, a certain activity may cause pain but may not require physical exertion. For example, a participant may say something like, “Yesterday I was chopping vegetables, and it hurt my hand a lot.” The interviewer will want to clarify if the activity was simply painful or if it actually required physical effort by referring the participant back to the intensity classification chart.
- Watch out for “activity skippers.” These are the people who only report major events and forget the activities they did for short durations. For example, an interviewer might ask a participant what he did in the afternoon. He might respond, “Oh, I went shopping.” In this case the participant has failed to report all of the activities he did such as getting ready, getting to the store, etc. The interviewer must always be thinking logically – “If the participant went shopping, I should rewind and ask about getting ready and getting there.”

GENERAL TIPS FOR INTERVIEWERS

1. STICK WITH THE SCRIPT

To ensure that all participants receive the same instructions for completing the PARA-SCI, it is important to carefully follow the script provided. The challenge, however, is to read the script in a tone that sounds conversational. Avoid sounding as though you are reading by familiarizing yourself with the script. In the beginning, read the script over several times so that you are comfortable with it before conducting your first interview. Once you have conducted several interviews, undoubtedly you will be able to recite parts of the script without even thinking about it. Be careful not to sound like a “broken record.” Try to remember to use your regular telephone talking tone.

2. PROBING FOR A RESPONSE

When interviewing, it is sometimes necessary to use a technique called probing. The purpose of probing is to obtain specific, complete, and relevant answers from a participant. An interviewer who probes well is natural and friendly and shows a real interest in the participant, while maintaining his/her neutrality regarding the participant’s answers. Without being overly aggressive or seeming to cross examine the participant, the interviewer works with the participant to obtain specific information for the researcher.

For example, when asking participants “How many times did you transfer?” sometimes participants give answers in ranges (e.g., “3-5”). If this occurs, probe the participant for a specific number. Say, “Would you say it is closer to 3, 5, or a number in between?”

It is especially crucial to probe “don’t know” and “refused” answers to minimize missing data points. When a participant answers “I don’t know” to a question it may mean one of several things:

- a) The participant is in a hurry to get the interview over with and does not want to take the time to think about an answer.
- b) The subject of the question is something the participant has never thought about before.
- c) The participant really has no idea of the answer.

In the first two situations, a remark such as, “I wonder if you could take a moment to think about it” is appropriate. In the third situation, the participant should be encouraged to arrive at an estimate.

When a participant refuses to answer a particular question, remind the participant of the information’s confidentiality. Initial “don’t know” responses and refusals should be probed **once** in an effort to obtain an answer. Of course, we are not suggesting that you should pester the participant to answer or convey the impression that you are annoyed by his/her inability or refusal to answer.

3 ACKNOWLEDGING STATEMENTS

Some study participants will be going through difficult life events (e.g., lawsuits, illness, surgery). At times, it may be appropriate to preface a question or respond to a comment with an acknowledging statement, such as “I know you’re going through a difficult time right now,” or “You have had to deal with a lot.” The best interviewers are those that are sensitive to participants’ needs and responses, while maintaining neutrality in how the participant responds. One can be responsive and caring while still giving the participant space to respond honestly, which is what “not introducing bias” is all about. In fact, if an interviewer fails to acknowledge when appropriate, the participant may react negatively.

4 KEEPING THE PARTICIPANT ON TRACK

Sometimes participants get distracted from the PARA-SCI interview and start going off on tangents. The best way to redirect a participant often depends on the specific situation. If a participant goes off on a tangent, the Research Assistant can try saying something like, “Now I’d like to ask you the next day of activities,” or “If you don’t mind, I’d like to finish the interview with you and then answer your other questions,” or “I don’t want to take up too much of your time, so let’s move on to the next day of activities.”

HOW TO RECORD PARA-SCI DATA

Page 25 contains an example of a completed PARA-SCI reporting sheet. The PARA-SCI reporting sheet is divided into three main columns representing the three recall days, with recall day 1 being the day previous to the interview date. Each day is divided into three main sections: **Morning Routine, Daytime, and Evening Routine**. The Morning Routine consists of the following rows: **Wake up time, Transfer, Bowel & Bladder Management, Bathing, Personal Hygiene, Dressing (Upper & Lower Body), and Other**. The Daytime section is divided into the following rows: **Breakfast, Morning, Lunch, Afternoon, Dinner, and Evening**. Finally, the Evening Routine is divided into **Bedtime, Transfer, Bowel & Bladder Management, Bathing, Personal Hygiene, Dressing (Upper & Lower Body), Positioning, and Other**.

Each recall day is divided into four columns. The first column is labeled **Activity**, and this is where a description and details of the physical activity are recorded. Next, the **Intensity** column is where activity intensity is recorded (mild, moderate, and heavy). In general, activities that do not require physical effort (i.e., “Nothing at All”) are not recorded on the PARA-SCI reporting sheet. For example, if a participant indicates that transfers do not require any effort, the “Intensity” box for “Transfer” would be left blank. The column labeled **Min** is where the duration of the activity is recorded in minutes. The final column labeled **Type** is where the activity is labeled as either LTPA or ADL. Always identify LTPA by marking “LTPA” in the type column. If this column is left blank, it can be assumed that the activity is an ADL.

DATA RECORDING TIPS:

Below are some simple tips for making data recording more efficient. The [sample](#) of a completed PARA-SCI reporting sheet provides examples of the tips listed below.

1. If an activity is completed each day for the same length of time and intensity, an arrow may be drawn into the columns for Day 2 and/or 3 to save time writing.
2. When recording complex activities, it often helps to give the activity a “title,” e.g., “Went to a doctor’s appointment.” Beneath this general heading, the activity can be broken down into its individual parts (e.g., wheeled from house to car, transferred into car, wheeled to doctor’s office), each likely having their own intensity and duration.
3. Note that the “Type” column is left blank for ADLs, and LTPA is identified by recording “LTPA” in this column.
4. Note that activities classified as “Nothing At All” in terms of intensity do not need to be recorded on the PARA-SCI.
5. Remember that a single activity may involve working at various intensities. For example, a wheel around the block that takes 20 minutes may involve 15 minutes of moderate intensity and 5 minutes of heavy intensity.
6. Some activities are repeated at various times throughout the day. Rather than rewriting the same information, use shortcuts. For example, if a participant indicates that they ran errands and transferred in and out of the car 6 times (for the same amount of time and same intensity), write x6 beside the duration.

PART 3:

**HOW TO SCORE
THE DATA**

MANUAL DATA MANAGEMENT AND SCORING

The scoring sheet (see below) organizes data by recall day, time of day (morning routine, daytime, evening routine), and type of activity (ADL, LTPA, total activity, = ADL + LTPA). Furthermore, data is organized by level of intensity for all three types of activity. The scoring sheet (below) contains columns for recording type of activity organized by Mild, Moderate, or Heavy intensity.

The type of data that is scored will depend on the type of data you are interested in collecting. You may be interested in collecting all data that the PARA-SCI captures, or only certain categories of data. For example, you may be interested in examining only leisure type physical activity completed at a moderate or heavy intensity.

Simply add up the minutes for the types of activity you are interested in looking at and enter the totals in the appropriate boxes of the scoring sheet below (e.g., moderate and heavy LTPA completed during the daytime). Please refer to the completed sample PARA-SCI recording sheet (page 25) and a corresponding completed data scoring sheet (page 28) as an example.

TIME X		MILD			MOD			HEAVY		
		ADL	LTPA	TOTAL	ADL	LTPA	TOTAL	ADL	LTPA	TOTAL
Day 1	Morning Routine									
	Daytime									
	Evening Routine									
Day 2	Morning Routine									
	Daytime									
	Evening Routine									
Day 3	Morning Routine									
	Daytime									
	Evening Routine									

PARA-SCI DATA MANAGEMENT PROGRAM

We have developed a program that can be used to input, manage and analyze PARA-SCI data. This program is ideal for use with large sample studies, or repeated measures designs. With this program, you can input and save all of the data collected on the PARA-SCI scoring sheet (i.e., activity type, intensity, duration). In repeated measures designs, multiple scoring sheets can be added to the record/data base for each individual participant. The program will also calculate average min/day of activity across the 3-day recall. Filters can be applied to calculate the average for specific types of activity. For instance, you may wish to calculate the average just for moderate intensity LTPA; or for 'wheeling' at a heavy intensity; or for total ADL. The program can be used to calculate these specific values (and many others), for each participant.

The program is a free download available on the SCI Action Canada website. We cannot provide any tech support for the use of this program. The following sections detail some basic instruction on how to use the software.

DATA ENTRY

Note: This program can be run on both Mac and PC. However, you cannot combine datasets between computers.

1. Open PARA-SCI program
2. Enter database password
3. Enter in your user name and password
4. If entering follow-up data, find the participant's ID number. Or click *Add New Participant* if entering a new participant.
5. Click *View Details*. The next screen will have a record of what has been entered for this participant. You may view an old entry or click *Add Entry* to input new data. A pop-up will ask you to enter their time period reference name—(e.g., Time 1, Time 2). Click *View Entry* on your new entry to add data.
6. Add all data. At the top left corner, you will notice that you are on Day 1 by default. On the left side of the screen, click the part of the day that there was some activity. Then, on the right side, click on the dropdown box of either *ADL* or *LTPA* (depending on what type of activity the participant engaged in). Click the dropdown box of *Intensity* to specify intensity level. Type in how long the participant engaged in this activity for in the *Duration* box. Click *Add Entry*. Continue to do this for all activities throughout the day and repeat for days 2 and 3. If day 2 is very similar to day 1, you may want to click *Copy activities to next day* and then make any necessary changes for this day. You can do the same for day 3.
7. If you incorrectly entered in an activity and need to delete it, simply click on the activity and click *Delete Entry*.
8. When you have entered in all of your data for the 3 days, click *Save Entry*. You'll notice that there will not be a pop-up asking you to confirm that you wish to save—don't worry your data has been saved. It's okay to click *Save Entry* a couple times if you want to be sure it was saved. *Sometimes when clicking 'save entry' it will copy the last entry again, watch the activity list to ensure an extra entry is not added.

Extras:

- Select 'Copy activities to next day' if there are similar activities between days. It is advised to enter morning and evening routines first (those are typically similar from day to day), then copy. You will have to click the 'Copy activities to next day' from the day 2 tab for activities to copy to day 3.

DATA ANALYSIS

1. To generate reports, click on the report tab. You can choose to apply filters based on the type of physical activity information you want to analyze (e.g., LTPA, ADL, low intensity, moderate intensity, wheeling, sports, etc.). If you do not wish to apply filters to the data, do not select any options. Click 'Apply filter' to generate your report.
2. At the top right corner, click *Main* to return to the main menu, *Participants* to enter in data for another participant, or *Logout* if you are finished and wish to exit the program.

INSTALLING PARA-SCI PROGRAM ON A NEW COMPUTER

1. Drag and drop the “PARA-SCI.air” folder from the current computer onto a USB key.
2. Plug the USB key into the computer that does not have the PARA-SCI program installed.
3. Opening “PARA-SCI.air” on the new computer will prompt a bunch of “Adobe-related” installations. Agree to these terms.
4. You may have to install ADOBE AIR in order to run the program.
5. The PARA-SCI should now be installed on computer
 - a. You should be able to find the program when you open the windows start menu and search under all programs.
 - b. For easier access, you can create a “short cut” for your desk top.

TRANSFERRING A PARA-SCI DATABASE FROM ONE COMPUTER TO ANOTHER

Note:

- *We can only REPLACE data, which means there can only be ONE master copy of a database on a computer.*
 - *In other words, DO NOT enter data on two separate computers and try to “MERGE” these files together.*
1. Go to “My Computer”
 2. Click on “C:” to access
 3. Double click on “Users”
 4. After this, you should see a folder with your name or organization on it (e.g., in my case, this folder simply says “KMG”, yours may say “XXXXX University”). Open this folder.
 5. You will now see a folder called “AppData,” open that folder.
 - a. If you cannot see “AppData”, you may need to change your viewing capabilities to allow “Hidden folders” to be seen.
 - i. Click on the “Organize” tab on the top left of the screen (or equivalent)
 - ii. Click on “Folder and Search Options” - “View” - then select “Show hidden files and folders”
 6. Once you have opened “AppData”, you will need to open the folder titled “Roaming”.
 7. Open the following folder: “ParaSCI.6BA4F718417EB83CC8552543F01101B3AFDA3017.1”
 8. Open the “Local Store” folder.
 9. You will now see the database files of whatever you have been working on (just check the date modified for whichever database is most recent).
 10. Copy this database and paste it onto your USB key.
 11. Place your USB key in the computer that has the version of the PARA-SCI Data that needs to be updated.
 12. Drag and drop this new database into the folder where the older database is currently installed
 13. The computer will prompt you “Do you want to replace?”. Selecting yes will install the newest data into the PARA-SCI system.
 14. Verify the accuracy of the new database by comparing reports from each computer

PART 4:

SUPPLEMENTARY MATERIALS AND RESOURCES

POSSIBLE DAILY ROUTINE FOR A PERSON WITH SCI

The following illustrates a possible daily routine for a person with SCI:

Wake up 7:00 a.m.

MORNING ROUTINE

Transfer out of bed
Wheel to bathroom
Transfer onto the toilet
Balance on the toilet
Transfer off of the toilet
Transfer into the shower
Balance in the shower
Washing
Transfer out of the shower
Wheel to the bed
Transfer into bed
Dress lower body
Dress upper body
Stretches
Transfer out of bed
Stretches
Make Bed
Wheel to Bathroom
Brush teeth
Blow dry hair
Put make-up on
Wheel to Kitchen

MORNING

Prepare Breakfast
Eat breakfast
Clean up
Read the newspaper
Wheel around inside of home
Get dress to go out/pick up items
Open the door
Wheel down the ramp
Transfer into car OR with elevator transfer into driving seat & secure chair
Lift chair into car
Driving
Lift chair out of car OR with elevator transfer into chair
Transfer into chair
Wheel to destination (up ramps)
Open door
Wheel inside to destination
Get undressed (i.e., take off coat put bags down)
Complete activity at destination
Wheel to bathroom
Open door
Transfer to toilet
Balance
Transfer off of toilet
Open door

Wheel back to destination
Get dressed/pick up items
Wheel inside to car
Open door
Wheel outside to car (down ramp)
Transfer into car OR with elevator - transfer into driving seat & secure chair
Lift chair into car
Driving
Lift chair out of car OR with elevator - transfer into chair
Transfer into chair
Wheel to house(up ramps)
Open door
Get undressed
Wheel around inside house

AFTERNOON

Prepare lunch
Eat lunch
Clean up
Transfer to toilet
Balance
Transfer off of toilet
Wheel around inside house (clump all together for the afternoon and evening)
Work on computer
Get vacuum out
Vacuum
Put vacuum away
Transfer to toilet
Balance
Transfer off of toilet

EVENING

Prepare dinner
Eat
Clean up
Transfer to the floor
Play with kids
Transfer to chair
Put kids to bed
Transfer to couch to watch television
Transfer off of couch
Transfer to toilet
Balance
Transfer off of toilet
Wash up
Brush teeth
Get clothes for next day
Transfer into bed
Undress lower body
Undress upper body
Dress lower body
Dress upper body
Get positioned in bed

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PARA-SCI ADMINISTRATION SCORING MANUAL

Participant ID #: _____ Initials: _____ Interviewer: _____ Date: Wednesday September 9

For each activity indicate: 1. Duration (min) 2. Intensity: Mild = mild, Mod = moderate, Heavy = heavy, NNA = nothing at all 3. Type: ADL or LTPA

Be sure to record the date!		Day 1: Date: Tuesday September 8				Day 2: Date: Monday September 7				Day 3: Date: Sunday September 6			
		Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Morning routine	Wake up time	7 a.m.				6:45 a.m.				9 a.m.			
	Wake up time		mod	2									
Bowel & Bladder Management							mod	15					
	Bathing	Shower	mild	10									
Personal Hygiene													
	Dressing	Lower Body											
Upper Body			mild	5									
Other													
			mild	3									
Breakfast													
		Washed and dried dishes after breakfast	mild	20						Made breakfast for family: -wheeling around kitchen -mixing pancake batter	mild	15	

PARA-SCI ADMINISTRATION SCORING MANUAL

Be sure to record the date!	Day 1: Date: Tuesday September 8			Day 2: Date: Monday September 7			Day 3: Date: Sunday September 6					
	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Morning	Went to doctor's appointment. -Wheeling between house and car -Transfer into car -Transfer out of car -Wheeling to doctor's office -Wheeling up ramp -Wheeling back to car	mod mod mod mod heavy mod	5 x 2 3 x 2 3 x 2 5 5 5		Went to the gym -wheeled to the gym -Arm cycling -Theraband exercises -wheeled home from the gym	mod mod heavy mod mod	15 20 5 15 15					
Lunch												
Afternoon	Swept the floor Transferring laundry into washing machine, and then back into laundry basket	mod mod	15 8 x 2		Rearranged boxes in the garage - lifting and lowering boxes	heavy	10		Standing frame exercise	mod	15	
Dinner												

PARA-SCI ADMINISTRATION SCORING MANUAL

Be sure to record the date!		Day 1: Date: Tuesday September 8			Day 2: Date: Monday September 7			Day 3: Date: Sunday September 6					
		Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Evening		<i>Wheeled around the neighbourhood</i>	<i>mod heavy</i>	20 10	LTPA LTPA					<i>played catch with son</i>	<i>mod</i>	25	LTPA
Morning routine	Bedtime	<i>10 p.m.</i>				<i>10:45 p.m.</i>				<i>10:15 p.m.</i>			
	Transfer		<i>mod</i>	2									
	Bowel & Bladder Management												
	Bathing												
	Personal Hygiene												
	Dressing	Lower Body	<i>mild</i>	5									
		Upper Body	<i>mild</i>	3									
	Positioning												
	Other												

TIME X		MILD			MOD			HEAVY		
		ADL	LTPA	TOTAL	ADL	LTPA	TOTAL	ADL	LTPA	TOTAL
Day 1	Morning Routine	18	0	18	2	0	2	0	0	0
	Daytime	35	0	35	42	20	62	8	10	18
	Evening Routine	8	0	8	2	0	2	0	0	0
Day 2	Morning Routine	18	0	18	15	0	15	0	0	0
	Daytime	0	0	0	30	35	65	10	5	15
	Evening Routine	8	0	8	2	0	2	0	0	0
Day 3	Morning Routine	18	0	18	2	0	2	0	0	0
	Daytime	15	0	15	18	20	38	0	0	0
	Evening Routine	8	0	8	2	0	2	0	0	0

APPENDIX

STUDIES THAT HAVE USED* OR CITED THE PARA-SCI

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